

## When the Family Requests Withholding the Diagnosis: Who Owns the Truth?

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In the United States, patient autonomy is a strongly held ethical principle.<sup>1</sup> Although this right to self-determination has not always been the norm in health care, it has become the foundation for all our patient interactions, such as the standard practice of providing sufficient, understandable information to a patient before obtaining consent for treatment.<sup>2</sup> Most recently, this concept of autonomy has extended to the practice of telling patients the truth about their diagnoses and prognoses.<sup>3</sup>

### Vignette

Mr L is a 73-year-old Hispanic immigrant from Central America who comes to the oncology clinic accompanied by his wife and adult son. He has been referred by his family practitioner, whom he sees for hypertension. The patient has a 40-pack-per-year history of smoking and a 4-month history of productive cough and weight loss. His work-up reveals a right lower lobe 3-cm mass on chest x-ray. The findings are confirmed on a computed tomography scan, which also shows mediastinal lymphadenopathy and a 2-cm mass in the left adrenal gland. A needle biopsy of the chest lesion is diagnostic for non-small-cell lung cancer. A positron emission tomography scan shows increased uptake in the lung mass, mediastinal lymphadenopathy, and the adrenal mass.

The patient and his wife have been in the United States for 10 years and live with their son and his family. They both speak English fairly well but look to their son to translate major portions of the conversation. Before the initial discussion with the patient and family, the son asks to speak to the physician alone and requests that the physician not discuss the diagnosis with the patient, for fear that such information will cause him to give up. The son would like his father to receive chemotherapy but wants him to be told it is to treat an infection.

### Ethical Issues

Most oncologists in the United States would react negatively to this request for nondisclosure. However, the expectation that the patient has the right to know the truth has not always been the norm and still is not the norm in many countries, although the issue of nondisclosure is being increasingly debated world wide. This question about whether the disclosure of diagnosis and prognosis is in the best interest of the patient is actually centuries old, but in recent decades, there has been a reframing of the physician-patient relationship from one of paternalism, in which the physician alone makes the decision about disclosure, to one of shared decision making.<sup>4</sup> Many scholars and clinicians have written about this evolution, and bioethicists have championed honesty and the inclusion of patients in decisions about their medical care. Foremost among these scholars

is Katz, whose seminal work, *The Silent World of Doctor and Patient*,<sup>5</sup> remains relevant today. Katz argued that leaving the patient out of the decision making process is an affront to human dignity and autonomy. More recently, Beauchamp et al,<sup>2</sup> in their classic work, *Principles of Biomedical Ethics*, set out the principles that form the framework for biomedical ethics. Although the principle of respect for autonomy most frequently takes center stage in discussions about the rights of patients and the obligations of physicians, the principles of beneficence and nonmaleficence have a place as well in evaluating truth telling and nondisclosure, as in this vignette. Respecting the autonomy of the individual does not imply a one-size-fits-all approach to truth telling. It does not require "truth dumping," but rather, it should be applied in a way that promotes a trust-based relationship by taking into consideration the patient's preferences for receiving information, expressed desires about involvement in clinical decisions, and the role of the family as desired by the patient.<sup>6-8</sup>

In this vignette, the oncologist may well be concerned that without a truthful discussion of the diagnosis and appropriate treatment options with this patient, there will be a lack of trust between them, and the relationship will suffer or not develop over time because of it. In addition, a patient who does not know his or her diagnosis may not be able to assess the risks and benefits of a treatment decision. But the answer to this conflict between what the physician thinks is best and what the son is requesting need not be framed as an all or nothing solution. There are gradual and nuanced approaches to working through the concerns of a son committed to the care of an aging parent and fulfilling the responsibility the oncologist has to his or her patient.

### Cultural Considerations

We live in a culturally diverse country and frequently find that not all our patients and families relate to or accept the idea of individual, autonomous decision making.<sup>9</sup> Rather, in many cultures, the family makes the medical decisions when one of the members is sick.<sup>10</sup> These cultural differences also affect the view of truth telling. In some societies, such as that in the vignette, it is the responsibility of the children to protect their parents from bad news. In other societies, the physician informs the family before the patient. In Japan, for example, the family frequently receives the cancer diagnosis and clinical plan before the patient.<sup>11</sup> In China, often the patient and family regard the family as having the primary decision making responsibility.<sup>12</sup> The literature extensively records these many cultural differences, but knowing that these differences exist does not automatically solve the conflict brought about by a nondisclosure

request. Adding to the complexity that many cultural norms coexist in the United States for family decision making is the challenge that these norms are not uniformly embraced by all family members.<sup>13,14</sup> Recent immigrants and older family members may adhere to the practices of their home countries, whereas younger members may have assimilated different notions about who should make treatment decisions.

## Practical Approaches

So where does this leave the oncologist and clinical team caring for the patient? Fortunately, there are a number of excellent communication guides that have been developed, which are valuable in teaching how to approach difficult communication tasks.<sup>15-17</sup> In particular, Back et al<sup>16</sup> established the simple step-wise approach of SPIKE: setup, perception, invitation, knowledge, empathize, summarize, and strategize. In addition to these communication tools, the following are some practical approaches that may be of use in handling a request for nondisclosure. Language barriers can exacerbate cultural differences, and physicians should consider using professional translators to facilitate communication with patients and families.

*First, spend time developing an understanding of the family's point of view.* Demonstrating respect for the family's perspective early on may prevent positions from becoming adversarial. The genuine concern that the family shows for the patient in this vignette is a positive to be embraced; the point of disagreement is only how this value is being actualized. It is also important at this point to address the family's worry and anxiety. This will help in developing an empathetic relationship with the family going forward. What do they think will happen if the patient is told the truth about the diagnosis? Their concerns may well be motivated by a desire to protect the patient, who, if asked, may not desire to be protected. However, there may be situations in which a family member's requests are inconsistent with a physician's understanding of his or her moral obligation to the patient, and the physician must remember that his or her primary responsibility is to the patient.

*Second, understand the patient's true preferences for receiving information.* Using this vignette as an example, the physician might ask about whether and how the patient would like to receive information about the results of the tests that have been performed. There are a number of options here that all result in the desired goal of having the patient know and understand truthful information, if indeed he or she wants it. The patient may want to have all discussions directly with the physician; the patient may want the family included in all meetings at which test results are discussed, and treatment decisions are made; or the patient may want to hear all important news from family members.

*Third, take an incremental approach to resolving requests for non-disclosure.* Discussions with the family to understand their request and with the patient to understand individual preferences

for disclosure are critically important but not always sufficient. Conveying the information about the test results with their accompanying prognostic implications may require a gradual sharing of information in a way that allows the family to adapt and meet cultural obligations and, at the same time, permits the physician to live up to his or her professional obligations.

*Fourth, continue to work with and include the family at key time points, when there is new information to be conveyed and when there are decisions to be made.* These are emotional times for both the patient and family. If the news is bad, these are difficult times as well, and the entire family will need to rely on their cultural traditions for support. The more physicians show respect for these traditions, the more comfort they provide and more trust will result from such an approach at exactly the time it is most needed.

## Conclusion

Requests for nondisclosure are not rare, but they cause considerable distress for physicians who are used to an autonomy-focused approach to clinical decision making. With careful attention to the cultural issues of patients and families in our diverse society, we can achieve an understanding about what patients want to know and convey this information with compassion and sensitivity. This is, after all, the goal. It is the patient and not the physician or the family who ultimately owns the right to decide how he or she wants to exercise autonomy with respect to his or her own illness.

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